DOCUMENT RESUME

ED 311 665 EC 221 081

AUTHOR Todis, Bonnie; Singer, George
TITLE Stress and Stress Management in Families with Adopted Children Who Have Severe Disabilities.
PUB DATE 4 Apr 89
NOTE 42p.; Paper presented at the Annual Convention of the Council for Exceptional Children (67th, San Francisco, CA, April 4, 1989).
PUB TYPE Reports - Descriptive (141) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Adoption; *Child Rearing; Children; Coping; *Foster Family; Motivation; *Multiple Disabilities; Observation; *Parent Attitudes; Qualitative Research; *Severe Disabilities; *Stress Variables

ABSTRACT

Qualitative research methods were used to investigate the sources and methods of dealing with stress in eight families with adopted children who have severe developmental or multiple disabilities. The families, who had each adopted from two to 30 children, included "birth children" and, in some cases, foster children as well. The research methods used were participant observation in the families and unstructured interviews with parents, adoption agency workers, state children's welfare workers, and counselors who work with adoptive families. The study identified the rewards associated with adopting children who have disabilities as well as common sources of stress. Somewhat surprisingly, management of daily household tasks and child care routines were not listed as stressful. However, interactions with school and medical personnel and other professionals were extremely stressful for all families interviewed. Effective stress management techniques included focusing on successes of children and the benefits of living in the family to the individual children, maintaining contact with other large families with adopted children with disabilities, and occasionally, adopting another child with severe disabilities. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED311665

STRESS AND STRESS MANAGEMENT IN FAMILIES WITH ADOPTED CHILDREN WHO HAVE SEVERE DISABILITIES

Bonnie Todis, Ph.D.
George Singer, Ph.D.

Oregon Research Institute

Eugene, Oregon

Presented at the 67th Annual Convention of
the Council for Exceptional Children (CEC)
April 4, 1989
San Francisco, California

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Bonnie Todis
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Address correspondence to:

Bonnie Todis
Oregon Research Institute
149 W. 12th
Eugene, Oregon 97401
(503) 342-8445

EC 221081

BEST COPY AVAILABLE

ABSTRACT

Qualitative research methods were used to investigate the sources and methods of dealing with stress in families with adopted children who have severe developmental or multiple disabilities. The families, which had adopted from one to 35 children, included "birth children" and, in some cases, foster children as well. The research methods used were participant observation in the families and unstructured interviews with parents, adoption agency workers, state children's welfare workers, and counselors who work with adoptive families. The study identified the rewards associated with adopting children who have disabilities as well as common sources of stress. Somewhat surprisingly, management of daily household tasks and child care routines were not listed as stressful. However, interactions with school and medical personnel and other professionals were extremely stressful for all families interviewed. Effective stress management techniques included focussing on successes of children and the benefits of living in the family to the individual children, maintaining contact with other large families that have adopted children with disabilities, and, occasionally, adopting another child with severe disabilities.

Methods of providing support to families who adopt children with special needs are suggested.

STRESS AND STRESS MANAGEMENT IN FAMILIES WITH ADOPTED CHILDREN WHO HAVE SEVERE DISABILITIES

Purpose

The research for this paper was conducted as part of a project titled Family Support for Parenting Deaf-Blind Children, under a grant from the Office of Special Education and Rehabilitation to Oregon Research Institute. The purpose of the project was to learn about the sources of stress in families which have children with severe disabilities, including children who are deaf/blind, to find out how some families deal effectively with such stress, and to develop a program to teach stress management skills to other families.

Most of the families who participated in the Family Support project had one or two children with severe disabilities. However, some of the families had adopted many children (as many as 30), many of whom have multiple and/or severe disabilities. These families seemed to function as well, or in some cases better, than many of the smaller families. The personnel working on the project who came to know these families well were naturally intrigued by this phenomenon which seems to defy common sense and contradict our own experiences as parents. Another reason for studying these families in depth is that, at least in our community and in the Northwest in general, many of the children who have severe multiple handicaps who are served in public schools live in such families. It is estimated that 10 to 15 percent of the children who have severe or multiple disabilities in the county where this research was conducted reside in adoptive or foster homes. Adoption into a super-family, as they are sometimes called, is sometimes the only hope a child with severe handicaps who is a ward of the state may have of living in the community

rather than in an institution. In the case of a child with severe medical problems from an institution in Southeast Asia, for example, living in a super family may be the child's only hope of living at all. It is important for teachers and other professionals who work closely with these families to understand how they function, how they view their family and its individual members.

Methods

Qualitative research methods were used in this study. These methods included participant observation and unstructured interviews. In participant observation, the researcher and the respondents interact informally as the respondents go about their normal daily activities. The unstructured interview, according to Stainbeck and Stainbeck (1984), is the best way to learn about the perceptions of respondents, since the researcher does not know in advance what are the relevant questions to ask. In unstructured interviewing, relevant questions emerge from the interaction process in which the researcher becomes sensitized to what is meaningful to the respondent. Combining interviews and participant observations allows the researcher a wider knowledge base than that provided by either method used alone.

Qualitative research methods are well suited to the study of issues in which the perspective of the subject, or the insider's view, is of interest (Edgerton, 1984; Whittemore, Koegel, and Langness, 1986). This methodology overcomes many of the problems of restricting responses inherent in question-and-answer procedures, since topics are raised by the respondents or arise from observation of the respondents' activities.

Detailed field notes are recorded for each participant observation, and the unstructured interviews are transcribed verbatim. Analysis of qualitative

data begins early in the study and continues throughout. By reading field notes and transcripts, the researcher discovers potential emerging themes, explores these through further data collection, and revises his or her tentative theories on the basis of this new information (Glasser & Strauss, 1967). Analysis constitutes an integral part of the data collection process as it helps focus the research on themes and concepts relevant to the researcher's theoretical concerns. In the later stages of the study, analysis becomes more formal. The data are coded and sorted by category. Conclusions which appear to be supported by the data are "discounted" or interpreted in the context in which they were collected (Taylor and Bogdan, 1984). Conclusions which withstand this scrutiny may be presented with methodological contextual explanations, to readers who are then able to make their own judgements about the validity and relevance of the findings.

Research Procedure

Eight families were contacted and asked to participate in a study of how families with children who have disabilities cope with stress. All but one family accepted. During the first visit, each family was informed that they would be visited in their home by the researcher for a three-hour observation to be scheduled at their convenience, but preferably when most family members were present and participating in typical activities. They were also told that the researcher would later, at their convenience and at the location of their choice, tape record a one-hour opened ended interview during which the respondents would talk about sources of stress in their lives and how they deal with stressful events. In an informed consent form, the respondents were notified of the risks associated with their participation, primarily having to do with threats to confidentiality. The safeguards of the

confidentiality of the data were detailed. One parent agreed to the interview but not the observation because her family was experiencing a high level of disruption due to the adoption of a ninth child. Each family received $25 as a token of appreciation for their cooperation.

In addition, several individuals were interviewed regarding specific sources of stress which were mentioned by the families, i.e., dealing with professionals in the fields of medicine and education and the problems that often arise when adopted children reach adolescence. The interviewees included a support group of mothers who have adopted children through Children's Services Division (Oregon's children's protection agency which removes children from abusive or neglectful homes and locates foster or adoption placements); the facilitators of the support group; a counselor who specializes in working with families who have adopted children; a teacher of children who have severe disabilities, many of whom live in super families; a parent trainer from Crippled Children's Division who works with parents and their children who have severe disabilities in their homes; and three staff members of an agency which assists families who have children with disabilities in locating services and resources.

Observation and interview data were recorded as described in the methods section. In the later stages of data analysis, a computer program, The Ethnograph (Seidel, Kjolseth, & Seymour, 1985), was used to code, sort, and retrieve data.

The findings described in this paper represent a preliminary look at families who have adopted children with severe disabilities. The study deals with a small number of families over a short time in a small geographic area. This is not inappropriate. Unlike traditional methods of inquiry in the

social sciences, qualitative research does not require the collection of a variety of types of data from large numbers of subjects who meet certain criteria, but instead on obtains detailed accounts a small number of respondents who have some characteristics in common but whose differences in other important areas are also taken into account. The authors would welcome the opportunity to extend the scope of this research by including families from different parts of the country, perhaps with different sources of stress, with different family management styles, and different types of support and resources. Expanding the study in this way could not only help us understand stress and stress management more fully, it would also give us valuable insights into families who are providing a host of services to children with multiple, severe disabilities, many of whom you see in your classrooms everyday.

Description of Families

At the time of the study, the families had between 3 and 35 children, including nonadopted children, and had adopted between 2 and 30 children. The two smaller families were included in the study in order to compare the sources and degree of stress in families of different sizes, and because each family had a unique perspective on the adoption of children with special needs. One of the small families was headed by a single mother who had spina bifida, had adopted two children with the same condition, had given birth to one nondisabled child, and was providing foster care for a child with autism. The other family had raised four birth children, provided care for dozens of foster children and had adopted two of them after seeing them through life-threatening medical crises.

Looking at the numbers of children alone is somewhat misleading, since in

most cases those numbers include adult children who no longer reside with the family on a permanent basis. Figures 1 and 2 provide profiles of two of the larger families' living arrangements. It is important to note that the disabilities listed are those certified by the public school systems the children attend. Almost all of the other nondisabled children adopted by these families experience some degree of emotional distress related to their preadoption experiences. Problems related to these emotional issues often surface during adolescence.

In the larger families (9-35 children), all but one family had a similar history in terms of how they began adopting children with special needs. The exception was a single mother who works for an international adoption agency. Her job is to place children who have special needs, and all of her nine children came to her attention in the course of her work, either as she examined their files or when she visited orphanages in southeast Asia or South America.

The other families all stated that when they began adopting children they had no intention of adopting a child with a disability or even an older child or a child of a different race. As one mother put it:

> We had 2 kids, this was 17 years ago, and were big ZPG (Zero Population Growth) people. So we decided to try adopting. But I had all these limits. We could have a half-black baby but not an all Black baby. It had to be a baby, a newborn. We couldn't have a handicapped child because it would be too hard on our other kids." [She laughs and shakes her head.]

When asked how her criteria for adoptability evolved to allow her and her husband to adopt 20 children with moderately to profoundly disabling

conditions she replies:

> I don't know what happened. We got to know [a family] who adopted a baby who had Downs syndrome. At that time he was just the cutest little Downs boy you'd ever seen. And gee, we kind liked him, you know? And so we said yes to a Downs child. And then when they called up and said that she had cleft palate, cleft, lip, club foot, and a heart defect. I think, under normal circumstances, we would have been overwhelmed and said no. But I don't know why but we just said "Oh, we can do it. We can do it." I don't know. It doesn't make sense, cause that's quite a bit to take for a first handicapped child. You know, I just, I just, it was just an absolute blast. I loved it. I absolutely loved it. But from then on, age and handicap did not make too much difference, as long as the child was not autistic."

This pattern of gradually broadening the criteria for adoptability is confirmed by the respondent who works in the adoption agency:

> I've been doing this for awhile. Ten years. And I think that I pretty much know most of the families around the country in some way or other that have kids with special needs. Most of the families that we have that are adopting children with multiple special needs have already adopted before, so we already know them. Perhaps they adopted, well, an example I can give you is say, a family that starts out and they adopt a healthy baby and maybe the next child they get is a 5-year-old. Then maybe the next child they get may have multiple special needs of some sort. And so they sort of grow with each adoption. And mostly that's what, I can't even think of any exceptions, where almost all the families, I won't say 100% of the families that I know of, that have

adopted children with multiple special needs, kind of started out that way. They sort of start out small, so to speak, and work their way up.

Following this pattern, 10 to 12 years after their first adoption, the families who participated in this study have adopted children who have an array of disabling conditions, from mild to profound. Most of the families have some children who had disabilities at the time they were adopted that were related to poor health care or inappropriate medication. After months or years in the family, some of those children no longer experience disabling conditions.

Once a family has adopted a child, many agencies will call them when hard-to-place children become available for adoption. "Hard-to-place children" includes older children, nonwhite children, and children with disabilities. Sometimes the families accept the child outright, sometimes they agree to take the child as a foster placement until a permanent placement can be found. In some cases foster children are eventually adopted.

The largest family made a conscious decision to "take pretty much unplaceable kids." This is also the attitude of 3 other families, although none of the families claim that they can handle any child or any disabling condition and occasionally decline when offered a child with a specific disability. Families often worry that if they say "No" when the agency asks them to take a child, it will hurt their chances of being able to adopt at a later time. They find, however, that the agencies respect their right to set limits in terms of number of children, type of condition, timing of an adoption, or just not feeling right about accepting a particular child. The agencies continue to ask these families to take hard-to-place children, or to suggest other families who might want them.

These families tend to expand when children have a need for a home rather than when the family feels a desire for another child. Because this is the case, once a family starts adopting children with multiple disabilities, the family tends to grow rapidly. One family adopted 4 nondisabled children between 1973 and 1977. They adopted their first child with disabilities in 1978, and 20 more children over the next 9 years.

Rewards

It seems obvious that powerful reinforcers must be operating to allow the parents to maintain and continually enlarge their families. However, the parents have a difficult time identifying the rewards associated with their way of life. When asked directly they tend to say, "I don't know," or "Beats me." When the question is pressed, many parents say that it is gratifying to see children grow and mature and to know that they are providing a better life than child would have had if he had not come to their home, to feel that they are "contributing rather than taking" from the world. Others are pleased with the special relationships that develop between some of the children whom they have given the opportunity to be brothers and sisters. One mother sums up the altruistic motivations by saying:

> So many of these kids would have been nothing, left in institutions. And to know that at least a very teeny tiny percentage amount of the kids in the world that need homes...we're able to do that small amount. And then in the process we get their love. That's kind of neat.

All of the families indicated that seeing positive change and growth in the children is gratifying, although in the cases of children with severe disabilities, these changes are often subtle and apparent only to the parents. Professionals who work with adoptive parents stress that parent must focus on

small improvements in the child's functioning or in his or her relationship with the family. When improvements are too small, nonexistent, or too infrequent, parents experience a great deal of frustration. One mother expressed her distress over the small gains of her son who has multiple severe disabilities. They are considering placing this child in an institution because:

> There is just nothing, whatsoever, that he's giving back. He will cuddle, but he doesn't hold on to you, he doesn't hug you. And um, we are feeling that we would like, it sounds awful... I mean, we feel it sounds awful, we don't like ourselves saying that. But we are beginning to feel that, possibly we can be doing a lot more for the other type of children. And putting our energies on the other type of kids that we can help. And that we can see some progress. Cause he has not changed for 2 or 3 years. And he's getting bigger and bigger and heavier and heavier.

With older, nondisabled children who have been removed from abusive homes, the rewards are also often slow to appear. The relationships of such children with their adoptive parents may be stormy throughout adolescence. Only later will some parents be able to feel some satisfaction in knowing that they have "broken the cycle" of abuse, and possibly enjoy their relationships with their adult adopted children.

Counselors and workers in adoption agencies, including the adoptive mother in this study who works in an agency, speak of the opportunity for personal growth as a benefit of the adoption experience. Children who are difficult to parent because of physical and/or emotional disabilities seem to uncover parents' vulnerabilities and issues from their childhoods. If parents are able to confront these issues, work through them, and recognize the

progress they have made, the experience can be extremely rewarding.

Other rewards of adopting large numbers of children with multiple disabilities appear to be related to self-esteem. None of the mothers in this study worked outside the home or had since the early days of their marriages, with the exception of the single parent who worked at the adoption agency. The raising of large a large number of children was, in a sense, a full-time job that each woman had chosen. The addition of children who had multiple disabilities adds responsibilities which elevate the job to a career. One mother describes how her life changed when she adopted her first child who had disabilities:

> I was doing everything for [her]. I was doing all the programs at home that you're supposed to do for these kids, and everything else. And back then we only had a few kids and I was at the hospital all the time when she got her surgeries. It was an absolute blast. I loved it. That's what built up my reputation at Crippled Children's Division as being a mother that's really involved.

In view of the energy devoted to the managing of a huge household and the meeting of each child's incredibly complex needs, it would be surprising if the mothers did <u>not</u> take pride in the accomplishments of their chosen "career." However, parents in this study, particularly mothers, resisted and denigrated the pride they felt when their effort resulted in their children doing well. The feeling was referred to by several mothers as "false" or "selfish" pride. The same mother who described how much she enjoyed caring for her daughter said apologetically, "I know you shouldn't get your self-worth from how your kids are doing, but I just can't seem to help it, that's how it works." This attitude seems to come from counseling families received

prior to adopting or in connection with family crises over the years which advises parent not to hold themselves personally responsible for either their children's successes or their failures. Although this counseling is intended to protect parents from overidentification with their children and from blows to self-esteem when the children inevitably experience difficulties, it also has in many of these families the corollary effect of mitigating what would appear to be a legitimate reward of the family life they have chosen: being proud of one's contribution to the achievements of "kids nobody else wants."

Sources of Stress

If it is somewhat difficult to identify the rewards of producing and maintaining a family with children who have multiple disabilities, it would seem much easier to list the stresses associated such a life style. Potential sources of stress that come immediately to mind include housing, food preparation, clothing and laundry, caring for several children who need daily medical attention or behavioral training, living with several children (as old as age 8) who are not reliably toilet trained, lack of privacy, and fitting the needs of as many as 20 children into a daily routine. Somewhat surprisingly, however, none the parents mentioned any of these factors as sources of stress or appeared to be frustrated or impatient when they confronted these issues during observations and interviews. Because these issues are so much a part of daily life, it appears that families have long ago worked out ways of dealing with them. All of the families live in large houses which are arranged so that family members can cluster in several different areas or can have complete, though temporary, privacy. Many of the cooking, cleaning and laundry chores are assumed by the adolescents and school-age children. In fact, one woman who married into a family with 25

children after the death of her first husband says:

> I don't tell too many people this: I work much less physically hard with this family than with my own three children. I don't do most of the things around here. I have to train the kids to do them and that's what I spent a good deal of time today with. Writing out what it takes to clean the bathroom, then showing, and pointing out the mistakes that she may have made so next time it will be easier. It's more administrative. But I always thought it was going to be physical stressors, But is isn't.

To protect themselves from the chaos that would erupt every morning when faced with getting 15 children off to eleven schools on eight buses, as is the case in one family, families have developed elaborate organizational systems. In one family, backpacks and shoes are lined up by the door the night before. In all families, chores are assigned on a weekly or monthly basis, and everyone is held accountable for them. Older and more able children are assigned to assist younger children and those with disabilities. Children are paid for doing chores in most families, and parents have various methods of keeping track of how much each child has earned. One mother makes extensive use of lists which she carries with her in a day-time calendar. Besides lists of chores and payments for chores she now has lists of the children's birthdates, after being embarrassed once too often during IEP meetings by confusing the dates of birth of her 20 children.

The extraordinary medical, training and hygiene needs of the children are handled matter-of-factly and without complaint. Small improvements are noted enthusiastically, but the expectation seems to be that positioning, giving medication, and toilet training will be part of the daily routine indefinitely. Keeping track of medical appointments for several children

seems to be the most difficult task in this area. MOthers use small personal calendars or large calendars posted by the telephone, or both, to remind themselves of appointments which may have been arranged weeks in advance.

Babysitters are always available from a pool of adolescent children or married children living nearby, so couples are able to spend time alone together. One couple goes out every Friday night, a date that is "etched in stone." Other couples try to get out frequently and to take short vacations, but one couple says they are content to stay home and "have it be just us," meaning themselves and more than 20 children.

Although meeting the demands of daily life requires planning and organization from the point of view of the families, food, clothing, shelter and carrying out daily, home-centered activities are not major sources of stress, even when the families are large and many of the children have multiple disabilities. Personal attributes may contribute to the ease with which daily routines are managed. All of the parents interviewed in this study are healthy and energetic and seemed to have developed the skill of keeping track of several trains of thought at the same time. For example, during a participant observation, one mother simultaneously cleaned her purse, paid two boys for chores, monitored two preschoolers, and talked to me. Some of the parents also seem to tolerate a level of disorder which might be unacceptable in other homes. In one case, a pool table was covered and mounded high with unmatched, laundered socks, and dirty clothes waited in 4-foot heaps in the laundry room. While this arrangement seemed to suit this family well, other families have worked out complicated systems involving personalized baskets and bins and color-codes clothes in order to avoid such laundry bottlenecks.

One might think finances would be a source of concern for any large family, and, in fact, none of these families is wealthy. One single mother was on welfare at the time of the study because she was unable to work following an accident, the father of a smaller family is retired, and the father of one of the larger families was temporarily laid off from his job in a lumber mill. The fathers of the other families include a teacher, a postal employee, and a log truck driver, respectively, all jobs which allow the fathers to be home from mid-afternoon through evening. None of the families indicated that a shortage of money was a source of stress. In fact, the mother in the family in which the father was laid off stated that it was helpful to have him around the house throughout the day.

In some sense, however, financial considerations are a problem for these families. Part of the financial burden is relieved by subsidies from various sources, but several families complained about the rules for becoming and remaining eligible for the subsidies. One father described his frustration with the Social Security Administration:

> They have their own secret rules. And they don't tell you what they are. And they make you feel like you're taking money out of their own pocket. That's how you feel. And they make you feel like a criminal. You feel almost like you're guilty because you are asking for what the kids are due. We have 4 kids who should be getting social security every month. And it would help us. But it's just not worth the battle. We don't get social security for the kids now. Because of their bureaucratic stinkum.

Another family was reluctant to accept the $25 payment for participation in this study because it might cause one of their monthly payments to be reduced.

Dealing with school systems to obtain appropriate services for children with disabilities produces other bureaucratic hassles. The widow who married into a large family says:

> I guess I was so naive. I really thought, before I knew and lived in the family, that all special needs, special ed kids got the best. And I really thought that since the government decreed it then they were really getting everything that they needed. And they were wonderful programs that covered all their needs and I sat back on my royal haunches and thought that. And it is so far from true. I guess, previous to the law changing it was horrible, so I guess we can say it's come a ways. But they aren't getting nearly what they need. I was just blown away by that.

All of the families concede that the programs in the immediate area are far better than those available elsewhere. At least one of the families moved to this city because they wanted their children to receive those services, and the mother who works in the adoption states:

> I think this a good system, I really do. And I think they have good teachers. And I think a lot of people do know that. Maybe that' one reason why there are a lot of families here that have a number of kids, because there is a good system. If there was a lousy system you would not want a kid [with disabilities]. It would be too hard to fight it.

But even though the services are superior to those available elsewhere, parents talk at length about their frustration in dealing with school personnel. Many of the problems arise from a difference in opinion about what services are appropriate for a child. Teachers accuse parents of having

unrealistic expectations for their children, sometimes based on prognoses from medical professionals which conflict with the opinions of educators. Often school personnel feel that adoptive parents overestimate the positive effects that a favorable environment, provided by their home, will have on the functioning of a child with disabilities. Such parents may demand services which the schools feel are inappropriate, or may lay the blame entirely on the schools if the child does not progress as expected.

Some parents resent what they consider to be the condescending attitudes of the professionals with whom they must negotiate to get services for their children.

> Can you imagine? Put yourself in the parents' place. There are as many as 8 or 9 people all sitting, all dripping Ph.D.'s and masters, and here the parent is. All these experts. It should be helpful to the parent. But [they] treat us like we're the isolated people and we don't know anything. They're the educated people who really think that they know best for our child. That puts us at odds immediately.

Parents feel that the expertise they have gained in living with and training their children should recognized and not discounted by educators.

Another source of frustration for parents who are new to adoption of children with disabilities is the discovery that there is not a <u>single</u> special education system, but several systems provided by separate bureaucratic entities, which sometimes overlap but more often leave gaps in service delivery. For example, parents who have heard that a particular city has a good special education system may discover that services for students with EMR are excellent, but that the services provided for their children with TMR are provided by a county service organization and require that their children

by bussed long distances.

Such problems are not unique to families who have adopted children with disabilities, of course, but are familiar to any parent with a child who require special education services. However, the large numbers of children involved and the number and severity of their conditions exacerbates the problem for these families. As one mother puts it:

> I understand why they have to have [IEP meetings] and all, you know, all the annual reviews, but sometimes you get just tired. Basically you just say the same thing every single time.

On the positive side, some parents who have worked patiently and assertively with special education providers over the years have earned the respect of teacher and other school personnel. One mother has had a child in almost every special education classroom in town, and because she has good working relationships with teacher and administrators, the family does not face a battle each time a newly adopted child enters the public school system. In fact, teacher often act as her allies, as when a dispute arises with a medical professional or another specialist over the proper treatment of a child's disability. During a district-wide teachers' strike that closed the schools, many of her childrens' teachers came to the home to provide academic instruction, hearing and speech training, and physical therapy.

There is a price to be paid for such consideration, however. This mother attributes her success in dealing with the schools to the fact that they see her as a "super-human person."

> When a nurse or a teacher or someone gets irritated because I didn't make it to an appointment on time, which was unavoidable for whatever reason, then I begin to feel guilty because I'm fulfilling that super-

> human person that they think I am. That, I don't necessarily want them to think I am, because the teachers that I'm closest to know I'm not.

However, being seen as extraordinarily competent, organized, and involved in her children's education allows her to command the respect of the service providers. When her ability to maintain the gruelling schedule of appointments inevitably breaks down, she feels that she may be jeopardizing the standing she has fought so hard for and on which the tailoring of services to her children's needs depends.

Parents in two of the larger families (20 and 28 children, respectively) expressed mild regret and frustration in regard to not being able to keep up a "super human" pace or to "keep all of the balls in the air." The father in one of these families said,

> I guess the main frustration to having this kind of family is you would like to spend more time with each kid, to be sure you were doing the most for them possible.

He felt he and has wife had been capable of doing that when they had only 15 children. The mother in the other family was somewhat embarrassed that she did not know, without referring to notecards, the birthdates of all of her children. From the point of view of these and the parents of the other families, the main reason they are "spread thin" and sometimes feel inadequate is not that they have more children than they can care for, but that the social service providers which are intended to be their support system do not provide enough of the services they feel their children need. Furthermore, when services are available, an extraordinary amount of the parents' time is required to achieve access to them and coordinate them with the families' other obligations. The parents' attitude seems to be that they could handle

almost any crisis, disability, or number of children, if only the service agencies, medical community, and schools were providing better and more accessible services.

Sometimes these families feel that their problems with public agencies are due, in part, to the fact that they have an unusual lifestyle and are highly visible. This sometimes makes them the object of prejudice and unfair scrutiny. Mothers contend that teachers "always assume that a problem at school is caused by something going on at home," or "if there's a break-out of head lice, boom, 'You guys caused it!"

Conversations with teachers and other providers of special services reveal that these professionals often do have reservations about the quality and quantity of the training available in a home with so many children with severe disabilities. As an adoption worker puts it:

> I'll tell you, I've worked with these kids for a long time and I do not see, it is inconceivable to me, how one of these really huge families can possibly begin to meet the needs of a lot of our kids who come out of these incredibly need situations, and have all kinds of particular issues that they're dealing with and have to learn to really begin to trust somebody as a source of stability.

A teacher expresses her concerns in this way:

> My bias comes from being a teacher, and I wish there was a way of getting families to sometimes change the way they interact with the child for the child's benefit, and I find these families particularly noncompliant and unwilling to try new things. I think given the numbers that they have to deal with, from the beginning they figure some way of operating, and it may be by getting siblings to help, it may be by not expecting very much

> from kids, letting them just be in preferred activities, let them go play, let them go watch tv, whatever it may be. They perceive any kind of a change as, you know, "My god, I'm dealing with all this and now you want me to do da, da, da," or "You have no idea how difficult it is in our home." I've been told, flat out, "Just don't bug me with this stuff. I'm not interested." And kids that are really at real severe risk when they are teenagers because of behavior disorders that with really not very much change, with just having some simple reinforcement system and knowing how to do time out effectively, they could really turn around.

This teacher's comments raise valid concerns about the extent of training that takes place in the home, but other professionals' concerns go even deeper, to a distrust of the motivations of the parents of these families:

> It seems to me that in families who adopt large numbers of kids, that there may be, at least in my experience three ways to explain that. One would be that they tend to be real religious and that this is sort of their mission--to take these kids in. Another is that they do it for financial reasons, that they have built a family economy around adopting or providing foster care for large numbers of kids, and a third is kind of--it's an addiction that borders on a sickness--that it's a real rush when the kids arrives and everybody gets excited and you have to make all these sorts of changes and that after you've done it a couple of times that as the family starts to stabilize and things start to kind of get worked out, there's a level of discomfort because everything seems to be going too well and it's time to get the rush again.

Another adoption worker says:

> With a number of super families I feel there's almost a neurotic need to do this. They need the approval, the admiration of the community, the agency, that this is almost more important to some of them than the actual relationship with the child.

Even if professionals who work with large families who adopt children with multiple disabilities do not openly express these views, such negative attributions are likely to be sensed by parents, interfere with communication, and strain relations between home and public agency. Parents are sensitive to the view of them that is held in the community, and the methods they have developed for coping with stress reflect that awareness, as we will see later.

Other stresses experienced by these families are common to most families, regardless of size. One family, whose 28 adopted children have come to them mostly from adoption disruptions, states unequivocally that the "biggest source of stress is teenagers." Parents in each of the other families also indicated that coping with the emotional upheaval and erratic behavior that accompanies adolescence is extremely stressful. Examples of problems associated with adolescent children in these families include sexual abuse of younger children by teenage boys; pregnancy, either of daughters or the girlfriends of sons; delinquent behavior including drug use and stealing from the family's church; verbal abuse directed at adoptive parents; and running away. While all families with teenagers are likely to experience some degree of difficulty, the problems in these families are multiplied, not only because they have unusually large numbers of adolescents but also because of the previous histories of those adolescents. All have been given up by their biological parents, or have been removed from their home because of physical or sexual abuse, but many have also been rejected repeatedly by foster parents

or adoptive parents. Some of the children have experienced 8 or 10 adoption disruptions by the time they come to these families as young adolescents.

Like all parents, parents in this study worry about the health and safety or their children and whether they will become happy, independent adults. There were indications in the course of this study, that an additional source of stress in the future might be the care of adult children with severe disabilities. Although none of the families in this study has confronted the issue yet, all referred to it in their plans for the future. Some families say they are content to have the children with the most severe disabilities live at home "forever." In some cases, arrangements have already been made for older children to take over when parents are unable to care for the disabled child. Other families speak of wanting to travel during their retirement years and wonder how they can manage that with adult children who have extraordinary care needs. Some parents have begun, reluctantly, to consider future institutionalization of their children whose disabilities are profound. Concerns of this kind also prevent some families from accepting children who have certain kinds of conditions such as autism or profound retardation.

Parents remain confident, however, of their ability to handle even the most disruptive adolescent crises and to accommodate the needs of their adult children who have disabilities, as long as outside agencies do not become involved. It is when law enforcement agencies or the state child protective services program or transition specialists enter the picture that parents report feeling stress. As one mother puts it:

> There is no stress within the family that we can't handle. It all comes from outside, from everybody wanting a little piece of us and our time.

Coping with Stress

The families in this study perceive that most of the stress in their lives results from contact with service providers who, they feel, offer inadequate services, make unrealistic demands on the family or child, and/or attribute uncomplimentary characteristics to the parents and the family as a whole. Not surprisingly, the method these families use to cope with stress is to distance themselves from its sources. This distancing cannot be physical, since the families are dependent upon the services provided by these professionals. Only in rare cases do families choose to do without a service entirely in order to avoid the stress associated with obtaining it. Families are able, however, to distance themselves psychologically from many of the sources of the stress in their lives. This is accomplished by constructing and maintaining a view of themselves which contradicts or ignores the negative attributions of other and focuses the families' attention on their own strengths, including a knowledge of each child's needs and strengths which, they feel, is superior to that of any service provider.

This strategy is seen clearly when the families cope with crisis situations, which, as in other families, often involve an adolescent getting in trouble or serious health or school problems of a child with disabilities. In such situations, these families report that they (1) focus on the accomplishments of other children; (2) focus on how much better off the child in crisis is than he or she would be in the previous situation; (3) adopt another child whose needs are even greater than the child who is in crisis; (4) turn to other families like their own for advice, sympathy, or instrumental support.

Each of these four strategies allows parents to bolster their self-

esteem at a time when the adolescent seems determined to destroy it through words and deeds or when the parents are in conflict with service providers over academic or health issues. In addition, some of these patterns of behavior produce benefits for the children of the family. The strategies are analyzed individually below:

(1) One of the strengths of these families which is readily recognized by adoption workers is that, because there are so many children in the family, with such a variety of problems, a great deal of pressure is removed from the individual adopted children. One adoptive mother has found:

> Quite a few of the adoption agencies are finding that they will place handicapped kids in large families because the parents can keep everything in perspective. And they have the other kids to give them their warm fuzzies. They don't concentrate too much on the problem.

Whereas a family that adopts one or two children expect those children to form a bond with the parents and allow them to have a "normal" family, there is no such expectation in the families in these studies. They recognize that the majority of the children they adopt will not "bond" in the same way that birth children do, since the capacity to do so drops dramatically as the child's age of entry into the family increases, and most of the parents have long since abandoned the idea that their family is the typical American family. Because parents have the problems and progress of many children to occupy their energies, there is latitude in such families for adopted children to express the rage many of them feel during adolescence in reaction to their early childhood experiences. Adoption workers interviewed in this study found large families more tolerant of these outbursts:

> These kinds of kids don't disrupt nearly as often out of these big, super

families. Those people have been there before, they know what's going to happen. And they'll tolerate more, and if you've got some of these kids that can't attach anywhere, you can see how this drives these Moms [of small families] crazy. Because they're looking for a normal child-parent relationship. These people [in large families], their attitude is, "We've got lots of other kids. Some of them will attach, and other kids need homes too." So they don't send them back because they didn't attach. That's probably the biggest strength, I think, of the larger families.

A counselor who works with adoptive families says:

The key for me always is the parent's ability to step back and not expect the kid to love right away... not to push a lot or put a lot of pressure on the child to change...These children are incredibly slow to change.

Parents of the families in this study are able to give any one child as much room as he or she needs because they have the affection of many children and because their self-esteem is not tied to the parenting of individual children but to the maintenance of the family as a whole.

(2) Adoption workers and other professionals have long recognized the absence of parental guilt as a strength of adoptive families. Unlike many parents who give birth to children with disabilities, adoptive parents do not experience a sense of guilt or shame, but rather have a sense of satisfaction or pride in their decision to take the child into their home. The adoptive parents, and many professionals, feel this gives them an advantage in working with school personnel and other service providers. As a social worker puts it:

It's really neat when families adopt a child with a handicap they don't

> feel the guilt that parents who have a handicapped child often have. They're a lot clearer about getting what they need for their child. They can be a really clear advocate. Because it doesn't get mixed up...They don't have to deny it. They don't have to feel like somehow it was their fault. It's not a reflection on them or anything. And they can just see what their child needs and get it.

A parent expresses the same idea in a different way.

> These are not our natural children so we don't feel guilty about bringing a child in the world that has Down's Syndrome. But a lot of parents do, for a long time, just ask and ask and ask, "What did I do wrong?" And they're embarrassed, and the feel like they are shunned and they probably are. And so to get them to even be in reality, let alone stand up and fight for their children...They just figure that the experts know so much more than they do that they must have done something very wrong, very stupid to bring a child like this in the world anyway. So to get those people together to fight for these kids, it's really hard.

The absence of guilt is also an asset during a family crisis. Because the families take children who were otherwise "unplaceable," unwanted by any other family, they are always able to reassure themselves that whatever the child's difficulties, they are less than they would have been in their previous situation. In most cases, the adoptive parents can also attribute the difficulties of the child in crisis to his or her history prior to entering their family. A teacher of children with severe disabilities, many of whom are adopted, sees the situation in this way:

> I think that [adoptive families] on the whole do not hold themselves at all responsible for how the children are. The fact that they're

handicapped or that they may have severe behavior problems or unusual health problems. So that those things are probably stressful when they come up, if the child has violent tantrums or has to be hospitalized or has a chronic illness. But I think there's, with biological parents, I often see the added stress of they blame themselves. And these parents don't blame themselves at all. And in fact there seems to be some kind of reinforcement involved in "Look at what we're dealing with. We have so much to deal with. We've taken on these kids that no one else will take on."

From an adoptive mother's point of view:

You want to make their life better than what it would have been living in an institution or whatever, you know. I think you just really need to consider, I think we all need to hang on to the fact that you're not going to rectify what's been done.

Or as another mother puts it:

Even in a birth child, if you've done your very best in parenting and you have done nothing that you can see, or that anyone can help you see that's helped to create the problem, then it's a lot easier to deal with it. You don't get hung up on the guilt.

This attitude is extremely helpful in confronting potential stress-producing parenting situations.

(3) Adopting a child with special needs is probably not frequently used as a strategy to offset the stress of parenting another child, but many adoption workers are aware that families employ it, consciously or unconsciously. In this study, one family had twice found that adopting a baby with a life-threatening medical condition had "solved" a problem they were

having with an other child. In both cases, the mother's energies and concern were entirely focused on the new baby, and her self-esteem was bolstered by the baby's progress.

(4) All of the families in this study are in regular contact with other large families that have adopted children with disabilities. In some cases, during difficult periods, mothers speak to one another on the phone several times a day. They report that this contact allows them to feel supported because the family's problems are considered normal rather than outrageous and the parents' feelings regarding the problems are also accepted nonjudgementally. Often when a family reveals a difficulty they are having, they find that other families have experienced the same problems, or worse. This allows them not only to learn from the other families' experiences, but also to assure themselves that the problem is not peculiar to their family and is not a result of their parenting style.

Many families learned to turn to other for support gradually after adopting their first several children. They remember that initially they were overwhelmed by the problems the children's special needs presented, but were unwilling to reveal their difficulties because the community or the adoption agency might see them as inadequate parents and possibly take the child or children away. Once they began to share their concerns with other families, however, they found their acceptance and understanding extremely reinforcing. Other adoptive parents are seldom able to offer solutions to particular problems, although families often take in an adolescent in crisis from another family for several weeks to give the family, and the adolescent, a break from tense situation. However, the element of contact with other families which provides the most support seems to be simply knowing that there are other

families in the area who have the same type of family with the same problems, who listen nonjudgementally and who understand implicitly what the family in crisis is experiencing.

Most families in the study also receive similar social support from their churches. The churches share with these families the emphasis on family life, sacrifice, the ideal of unconditional love, and helping those who are less fortunate. To the extent that the church leaders and the members of the congregation demonstrate their commitment to these values and their unconditional acceptance of the family's way of life, they become sources of social support. If, however, the family sense that the church's attitude is less than totally accepting, they will try a different congregation or forego church membership entirely.

Social support mitigates stress for these families in two ways. First, knowing that similar families face similar stress-producing situations allows parents to maintain their self-esteem and to avoid the added stress of questioning their parenting ability. Second, interaction among the families, to the exclusion of other types of social interaction, i.e, with single people or with small families, allows them to maintain a sense of separateness and a world view that is different from that of mainstream America. Contact with other adoptive families and with the church provides the families in this study with a community that gives them powerful positive reinforcement for choosing and maintaining their lifestyle.

Many counselors who work with families who adopt children emphasize the importance of parents maintaining their sense of "ok-ness" or self-esteem, and of their being at peace with themselves so they can be tolerant of the difficulties of their children. In most families, this would mean that

parents would reflect upon their contributions in their careers or in their communities to restore a sense of equilibrium. For the parents in this study, all of the strategies used to mitigate stress by restoring self-esteem relate to the most salient feature of the parents' lives: the fact that they adopt large numbers of children with special needs. Their families represent not just a life-style but the central organizing feature of their lives from which they derive their self-worth. The strategies they use to bolster their self-esteem during stressful times all involve turning their attention and energies to the needs of the family, or even creating additional needs of the family by adopting another child. It appears that in order to face the stress of crisis situations, parents of these families must reassure themselves of the fundamental "rightness" of their world view and of the task they have undertaken. Any other approach might cause them to question the wisdom of undertaking so many responsibilities and to wonder whether the crisis itself may have resulted in part from the structure of the family. In order to avoid the additional stress of such self-doubt, the parents have developed a stress management system which insulates them from these troubling thoughts and allows them to confront, more or less continually, situations which would be devastating to most families.

Supporting Adoptive Families

As indicated in the first section of this paper, adoption represent an important option for community integration of children with multiple and severe disabilities who are given up by their parents at birth. If such children are not adopted, the options for their residential care are limited to institutionalization, group homes, or foster care, all of which are considerably more expensive to the service system and less in line with

normalization principals than adoption. Since the vast majority of children with disabilities who are adopted reside in super families, providing support to these families may, therefore, benefit not only the children and their parents but also the social service system and society as a whole.

This paper suggests some ways in which service providers can help these families avoid stress-producing situations or cope with the stress they will inevitably encounter. Appropriate educational services must be available for all children. Procedures for obtaining financial and medical assistance should be streamlined. However, even if a full array of services were available for every child upon request, conflicts would arise between service providers and parents. Service providers tend to attribute these conflicts to parents' unrealistic expectations, while parents attribute them to rigid policies which fail to take into account the parents' intimate knowledge of their children's capabilities and needs. In order to improve communication, parents need accurate, detailed information about their child's disabilities and about the services available in the community prior to adoption. One service provider states that often families are:

> ... operating under mistaken impressions from whoever sponsored the adoption that things are being promised or that things are going to be available, that things will drop right into place that, in fact, don't happen.

A parent who has a disability herself concurs that knowledge of the child's disability is important in accessing services and dealing with professionals:

> I would suggest finding out just exactly what the disability is and doing a lot of research on it. Asking doctors, but also keeping an open mind, too. You know doctors have a tendency, not all doctors, but some doctors

> have tendency to make things maybe more dismal than what they need to be. Find out truly what kind of educational system that they have. And look at that child now, tomorrow and the day after, and what's going to happen when that child gets 21.

Preadoption counseling should, clearly, include thorough, realistic information on disability and the social service system.

Service providers, for their part, can improve communication with parents of super families by recognizing their unique contribution to the integration of children with disabilities into the community. Rather than focussing on the frustrating fact that parents' time and energy to work individually with individual children is necessarily limited in a family of 15 or 20, some teachers and other professionals credit super families with producing children who have excellent social skills and adapt readily to new situations. As one social worker puts it:

> Most of the families that I've been involved with, I think it's really neat. The kids are happier than they probably would be if they were in an institution, and the parents are doing the best they can. You know, maybe they <u>are</u> sick, but maybe it's good that they are. Maybe it's good there are some people like that, who will help out the kids.

Another professional states:

> If a family has raised 15 handicapped kids, then I think it's reasonable to say that they bring to an IEP meeting a body of expertise that in many ways exceeds that of the teacher, around how you manage certain issues and so on.

And a teacher finds:

> I think the first thing people have to realize is they're really

> important as parents. They do know their kids well. Professionals are excellent resources because they might be an expert on your finger or your knee, but the parent needs to put that altogether...to see it in relation to the whole kid and the whole kid in relation to their family.

Parents are asking of professionals if not this kind of respect then at least tolerance for their choice of lifestyle. Without this, relations between super families and service providers will be a constant source of tension.

Analysis of the daily lives of large families which include children with disabilities indicates that organizational strategies prevent household and childcare chores from becoming stressful. Families seem to learn these strategies through a process of evolution as they grow, or to pick up pointers from other large families. The super family network provides social support in many other ways as well, as outlined in the previous section. Many adoption agencies and counselors are mindful of the importance of this network in mediating stress and encourage parents who are adopting children with disabilities to establish this contact. Alternatively, or in addition, some families access the same type of social support from their church. Whatever the source of social support for these families, it appears to be critical that it comes from others who approve unconditionally the choice the families have made to make adoption of children with special needs the central feature of their lives. Encouraging parents of super families to join support groups composed of parents of one or two children who have no disabilities would probably not be beneficial and might even contribute to the stress of both types of parents. As one mother of a single adopted child pointed out:

> I suppose you've interviewed some of the super families? They're doing something entirely different, you know. We're trying to take one or two

kids and integrate them into an existing family. They're just trying to maintain.

Such perceptions are not likely to provide parents of super families with the implicit approval they need in order to feel cared for by their social support system.

One aspect of this study pointed out the importance of taking the perspective of the individuals who are the target of services. It is clear that when confronted with crisis situations, the families in this study focus on positive aspects of their childrens lives and of their family as a whole. However, for several of the parents, the power of this strategy is attenuated by advice from counselors which cautions against relying upon one's children's successes for one's own sense of self-worth. This advice is no doubt intended to protect parents by encouraging them to develop interests and sources of self-esteem outside of the family. If parents do not feel they are entirely responsible for their children's successes, they are also protected somewhat from blows to self-esteem resulting from children's difficulties. However, this standard advice fails to take into account the special circumstances of the super family, for whom the family is more than one aspect of the parents' lives but is, rather, for most, and particularly for mothers, the only area in which they want to focus energy and attention. Counselors and other professionals who work with these parents on stress management can help them most by reminding them to rely on the strategies the families themselves have developed: reminding themselves of the positive effects of their family life on the lives of their children, including those who are in crisis, and concentrating on their successes with their other children.

This study seems to indicate that families who adopt many children who

have disabilities <u>are</u> doing something fundamentally different from other adoptive families, and that the ways in which they cope with the stress associated with family life are also different and, for them, highly effective.

REFERENCES

Edgerton, R. B., (1984). Anthropology and mental retardation: Research approaches and opportunities. Culture, Medicine and Psychiatry, 8, 25-48.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine.

Seidel, J., Kjolseth, R., & Seymour, E. (1985). The ethnograph. Littleton, CO: Qualis Research Associates.

Stainbeck, S., & Stainbeck, W. (1984). Methodological considerations in qualitative research. Journal of the Association for Persons with Severe Handicaps, 9, 296-303.

Taylor, S. J. & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meanings. New York: John Wiley & Sons.

Whittemore, R. D., Koegel, P., & Langness, L. L. (1986). The life history approach to mental retardation. In L. L. Langness & H. G. Levine (Eds.), Culture and retardation (pp. 1-18). Dordrecht, The Netherlands: D. Reidel.

Family 1

Children Living at Home

Adopted children

Condition	Number	Age
Blind/deaf, profound retardation, cerebral palsy	2	19
Down Syndrome	2	15, 5
Severe Orthopedic Impairment, EMR	1	15
Lowe Syndrome	1	13
Nondisabled	2	13, 16
EMR	2	16, 17

Birth Children

Nondisabled	3	9, 11, 17
Total	13	

Adult Children Not Living at Home

Adopted Children

Disabling conditions (if any) unknown	7

Birth Children

Nondisabled	8
Total	15

Family 2

Children Living at Home

Adopted Children

Condition	Number	Age
Down Syndrome	2	9, 6
Blind, autistic (?)	1	2
Blind/deaf, profound retardation	1	8
EMR	1	11
EMR, Cerebral palsy	3	7, 8, 10
Nondisabled	6	14, 16, 16 18, 18, 18*
Cerebral palsy	1	10
Total	15	

Adult Children Not Living at Home

Adopted Children

Nondisabled	4

Birth Children

Nondisabled	2

Birth Children

* Staying with family friends temporarily